Pain: How to Recognize when it Hurts
Making Communication Happen Worldwide
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Objectives

Following the workshop, participants will be able to:

- Describe pain definitions and concepts
- Identify policies initiatives to improve pain assessment and management
- Discuss the prevalence of pain in individuals with complex communication needs
- Identify pain assessment strategies
- Use selected measures to help identify and quantify pain and distress in individuals with complex communication needs

What is Pain?

"Whatever the experiencing person says it is, existing whenever s/he says it does" (McCaffrey, 1968)

"An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage" (IASP)

Added (2002): "The inability to communicate verbally in no way negates the possibility that an individual is experiencing pain and is in need of appropriate pain relieving treatment"

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Biopsychosocial Model of a Pain Episode

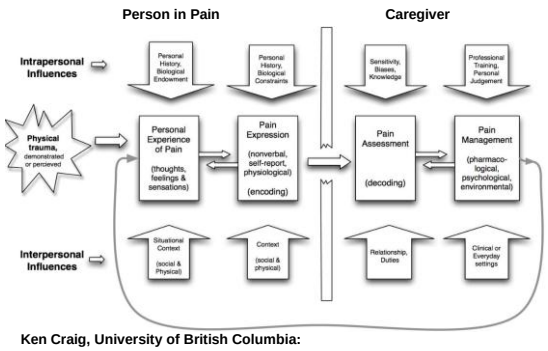
(Loeser & Fordyce, 1988)

Nociception
Process of signaling CNS about tissue damage are

Pain
Sensory perception of nociceptive stimulus

Suffering
Affective reaction to pain

Pain Behavior
↑ or ↓ in communication or behavior



Ken Craig, University of British Columbia:
The World of a Person in Pain: A Social Communications Model

Key concepts

- Pain is complex
- Subjective experience and self report is best, if and when possible
- Pain can exist in the absence of a known physical cause
- Pain has sensory *and* emotional dimensions
- Unrelieved pain has adverse physical and psychological consequences

Why is Pain Important?

- Humanitarian and ethical imperative
- Affects health and ability to function
- Long-term effects - may contribute to disability later in life
- Pain impacts the person, family and caregivers and society

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Is Pain Management a Problem?

Efforts to improve pain management

- 1992 AHCPR Acute Pain Management
- 1995 APS Pain: the fifth vital sign
- 2000 AAP Prevention and Management of Pain in the Neonate
- 2000 APS Pediatric Chronic Pain
- 2001 APS Assessment and Management of Acute Pain in Infants, Children, Adolescents
- 2001JCAHO Pain Management Standards
- Mandatory education in some states

Major improvements - problems persist

Pain and Health Disparities

Groups at greatest risk for unrecognized and undertreated pain

- Infants and children
- Individuals with disabilities and cognitive or communication challenges
- Older persons
- People representing racial and ethnic minority groups
- Individuals with limited English language proficiency

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International Association for the Study of Pain (ISAP)

- Cultural, political, attitudinal, educational, and logistical reasons for poor pain relief worldwide
- Unacceptable gap between knowledge & practice
- Pain relief is ethical and evidence-based
- Global Year Against Pain
  - 2004 Pain Relief as a Human Right
  - 2005 Pain in Children
  - 2006 Pain in Older Persons
  - 2007 Pain in Women
  - 2008 Cancer Pain
  - 2009 Musculoskeletal pain
  - 2010 Acute pain

http://www.iasp-pain.org//AM/Template.cfm?Section=Home

How Common is Pain in Individuals with Complex Communication Needs?

- As likely or MORE likely to experience pain from the same sources as others
- Common sources include:
  - ❑ GI problems/ constipation
  - ❑ Illness
  - ❑ Injury
  - ❑ Many

Some sources that may be overlooked

- ☐ Neuropathic
- ☐ Dental
- ☐ Musculoskeletal /Positioning
- ☐ Arthritis
- ☐ Headaches
- ☐ ENT

How Common is Pain in Children with Developmental Disabilities?

Pain Incidence in Children with Severe Cognitive Impairments (Breau et al., 2003)

- Cohort study
  - 94 caregivers of children and adolescents
  - aged 3-18 years
- Examined pain cause, frequency, duration, and intensity
  - using telephone surveys
  - over a 1 year period

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Pain in Children with Severe Cognitive Impairments, continued (Breau et al., 2003)

- Frequency
  - Each week, between 35% and 52% had pain
  - In a 4 week period 78% has pain at least once
- Duration
  - Mean duration was > 9 hours / week
- Intensity
  - Mean for accidental pain 3.8
  - Mean for non-accidental pain 6.1

Cerebral Palsy and Pain

(Jahnsen et al., 2004)

- Musculoskeletal pain in adults with CP compared with the general population
  - 30% of adults with CP had chronic pain vs. 15% in the general population
  - Back pain was the most common
  - Pain in adults with CP associated with gender, chronic fatigue, low life satisfaction and deteriorating physical function

Misunderstandings about Pain: Pain in children with autism

- "reduced pain sensitivity", "not feeling pain as intensely as others", "indifference to pain", "a high threshold for pain", etc. (DSM-IV TR, 2000; Wing, 1996; Bettelheim, 1967; Peters, 1999, etc.)
- anecdotal and clinical impressions
  - Nader, R., Oberlander, T.F., Chambers, C.T., & Craig, K.D. (2004). Expression of pain in children with autism. *The Clinical Journal of Pain, 20, 88-97.*

Nader, R., Oberlander, T.F., Chambers, C.T., & Craig, K.D. (2004). Expression of pain in children with autism. *The Clinical Journal of Pain, 20, 88-97.*

- 21 children with autism
  - (18 boys, 3 girls; mean age = 5.42 yrs.
- Intravenous hormone injections
- Nonimpaired comparison group (n = 22; mean age of 5.16 years
- received venepuncture for blood
- Videotaped;
  - Children's Facial Coding Scale
  - Observational Scale of Behavioral Distress

Tordjman et al. (2009). Pain reactivity and Plasma β- endorphin in children and adolescents with Autistic Disorder. *Plos ONE*, 4, e5289

- Children with autism showed ↑ heart rate & & ↑ plasma beta-endorphin during venepuncture
- reflects enhanced physiological and biological stress responses that were dissociated from observable emotional and behavioral reactions
- Prior reports of ↓ pain sensitivity in autism are related to *a different mode of pain expression and NOT* pain insensitivity or endogenous analgesia
- Clinical care practice and hypotheses re: underlying mechanisms need to assume that children with autism are sensitive to pain.

Pain and Complex Communication Needs- Additional Challenges

- Risk for additional emotional burden and suffering due to difficulties in ability to:
  - Understand pain as a signal of damage/ harm
  - Communicate effectively and get help
  - Predict what will happen & anticipate pain relief
  - Activate cognitive strategies to cope with pain

Summary and Practice Implications

- Individuals with complex communication needs are at high risk for under-recognition and under-treatment of pain
- Pain in this population has received little attention until recently
- Unrelieved pain reduces health and QOL for individuals, their families and caregivers
- Pain must be assessed and managed

Pain Assessment

- Improved pain management requires
  - measurement
  - on-going assessment
- Systematic
- Individualized

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What to measure?

- **LOCATION** (spatial)
  - *Where does it hurts. Does the pain go anywhere else in body?*
- **INTENSITY (sensory)**
  - ***How much does it hurt? Pain intensity scales***
- **DURATION** (temporal)
  - *When you have pain, how long does it last?*
- **QUALITY** (descriptions)
  - *What words might be used to describe the pain (sharp, burning)*
- **AFFECT** (emotional)
  - *How does the pain make you feel?*
- **INTERFERENCE** (quality of life)
  - *How does pain interfere with your functioning?*

Self-Report Measures

- Verbal format
  - Self-rating scales (e.g., numeric rating scale)
  - Pain adjectives
  - Questionnaires
- Non-verbal format
  - Faces scales –point
  - VAS – mark

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Behavioral Measures

- Used with infants and young children
- Children and adults with intellectual disability or communication needs
- Observe and quantify vocalizations, facial expressions and body movements
- Document changes in typical patterns of daily life (eating, sleeping and play)

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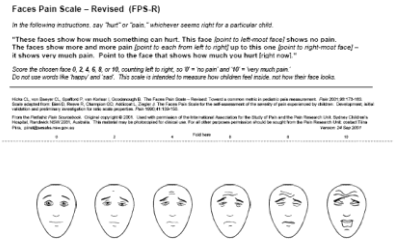
Faces Pain Scale-Revised

http://painsourcebook.ca/pdfs/pps92.pdf



Defrin, Lotan & Pick (2006)

- 65 adults with mild/moderate ID
- rated pain from influenza vaccination
- Most chose a "smiley" face before and after vaccination
  - Unable to use scale?
  - Vaccination not very painful (NCCPC-R change significant but small)
- Unclear at this time whether self-report of pain is sound for children or adults with ID
- Not recommended as the only indicator of pain

Hierarchy of Pain Assessment Techniques, McCaffrey & Pasero, 2005

1. Attempt to elicit a self-report and explain why self-report can't be used
2. Search for potential causes of pain
3. List patient behaviors that may indicate pain; use behavioral scales, if possible
4. Surrogate Reporting; list patient behaviors family/ parents caregivers think may indicate pain
5. Attempt an analgesic trial

Pain Measures for Adults with CCN

- **Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities (CPS-NAID)**
  - Burkitt, Breau, Salsman, Sarsfield-Turner & Mullen (2009)
- **Non-communicating Adult Pain Scale (NCAPS)**
  - Lotan, Ljunggren, Johnsen, Defrin, Pick, & Strand (2009)
  - Lotan, Moe-Nilssen, Ljunggren& Strand (2009)
- **Pain and Discomfort Scale (PADS)**
  - Bodfish, Harper, Deacon, Symons (Report; 2001)
  - Phan, Edwards, Robinson (2005)

Pain Measures developed by Breau et al. for nonverbal children and adults

- Non-communicating children's pain checklist-revised (NCCPC-R)
- Non-communicating children's pain checklist-post-operative version (NCCPC-PV)
- Chronic Pain Scale for Nonverbal Adults with intellectual Disabilities (CPS-NAID)

Available for free download to use in practice
http://www.pediatric-pain.ca/content/Measures

Lynn Breau's Recommendation re: Pain Measures for Adults at this time

Chronic Pain: Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities (CPS-NAID)
- Needs more research, but offers cut-off scores and early psychometrics are good
- Based on items that are highly valid & reliable in children

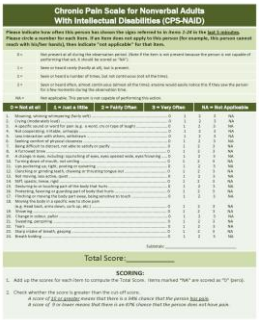
Acute / Procedure Pain: NCCPC-PV
- Some adults in most studies
- Age does not appear to affect scores
- Cut-off scores available

Non-communicating children's pain checklist-post-operative version (NCCPC-PV)

Breau et al (2002). Validation of the Non-communicating Children's Pain Checklist-Postoperative Version. Anesthesiology **96**(3): 528-35
- Participants: Caregivers of 24 children with severe intellectual disabilities aged 3-19 years
- Method: Child observed and pain rated by caregiver, researcher and nurse for 10 min before and after surgery using NCCPC-V and VAS
- Result: Score of 11 by familiar an non-familiar caregivers had adequate sensitivity and specificity for classifying moderate to severe pain

Chronic Pain Scale for Nonverbal Adults with Intellectual Disabilities (CPS-NAID)

Burkitt, Breau, Salsman, Sarsfield-Turner & Mullen (2009)

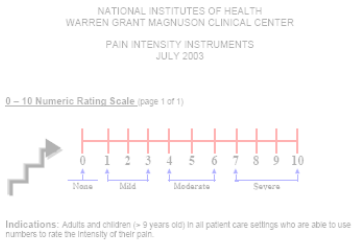


Chronic Pain Scale for Nonverbal Adults With Intellectual Disabilities (CPS-NAID)

Total Score:

SCORING:

Numeric Rating Scale



NATIONAL INSTITUTES OF HEALTH
WARREN GRANT MAGNUSON CLINICAL CENTER

PAIN INTENSITY INSTRUMENTS
JULY 2003

0 – 10 Numeric Rating Scale (page 1 of 1)

0 1 2 3 4 5 6 7 8 9 10

None Mild Moderate Severe

Indications: Adults and children (> 9 years old) in all patient care settings who are able to use numbers to rate the intensity of their pain.

The checklist of nonverbal pain indicators (CNPI). Feldt, KS. (2000) Pain Management Nursing, 1(1): 13-21.

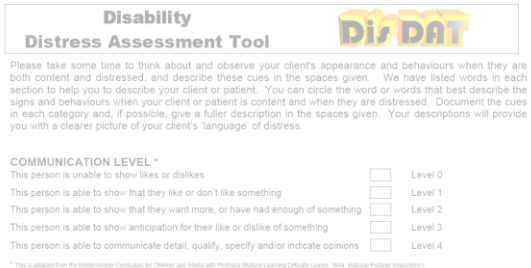
Vocal Complaints – nonverbal expression of pain demonstrated by moans, groans, grunts, cries, gasps, sighs)
Facial Grimaces and Winces – furrowed brow, narrowed eyes, tightened lips, dropped jaw, clenched teeth, distorted expression
Bracing – clutching or holding onto siderails, bed, tray table, or affected area during movement
Restlessness – constant or intermittent shifting of position, rocking, intermittent or constant hand motions, inability to keep still
Rubbing – massaging affected area
Vocal complaints – verbal expression of pain using words, e.g., "ouch" or "that hurts; " cursing during movement, or exclamations of protest, e.g., "stop" or "that's enough."

Disability Distress Assessment Tool

Regnard et al. (2007) *JIDR*, 51, 277-292

Not all distress behavior indicates pain

- Developed in UK by a palliative care team working with individuals with significant communication impairments http://www.disdat.co.uk/
- Uses behavioral signs to indicate distress, but makes no assumption re: the cause
- Can be used to monitor changes



Disability Distress Assessment Tool

DisDAT

Please take some time to think about and observe your client's appearance and behaviours when they are both content and distressed, and describe these cues in the spaces given. We have listed words in each section to help you to describe your client or patient. You can circle the word or words that best describe the signs and behaviours when your client or patient is content and when they are distressed. Document the cues in each category and, if possible, give a fuller description in the spaces given. Your descriptions will provide you with a clearer picture of your client's 'language' of distress.

COMMUNICATION LEVEL *

This person is unable to show likes or dislikes — Level 0
This person is able to show that they like or don't like something — Level 1
This person is able to show that they want more, or have had enough of something — Level 2
This person is able to show anticipation for their like or dislike of something — Level 3
This person is able to communicate detail, qualify, specify and/or indicate opinions — Level 4

Pain resources

- Oberlander, T. & Symons, F. (2006). *Pain in children and adults with developmental disabilities*. Baltimore, MD: Brookes Publishing Co.
- Centre for Pediatric Pain Research: Science Helping Children
  - http://pediatric-pain.ca/
- International Association for the Study of Pain (IASP)
  - http://www.iasp-pain.org/
- IASP Special Interest Group on Pain in Childhood
  - http://childpain.org/links.shtml
- American Pain Society
  - http://www.ampainsoc.org/